

# AIDS TREATMENT NEWS

**Issue Number  
387  
December 27,  
2002**

Published 18 times a year by  
John S. James  
AIDS Treatment News  
1222 L Street, Ste. 540  
Washington, DC 20005

## **Contents**

### **ADAP and Medicaid Financial Emergencies Growing..... 2**

Advocates are trying to limit the shortfalls that are keeping more and more people from getting medically necessary treatment.

### **Smallpox Vaccination Followup: IOM Suggests Changes, Widespread Civilian Vaccinations to Begin..... 4**

A new report from the prestigious Institute of Medicine, asked by the government to study smallpox vaccination program, urged several changes.

### **Boston: Community Forum on Retroviruses Conference, Feb. 14 5**

Search for a Cure organized this report to the community on new treatment information from the 10th Conference on Retroviruses and Opportunistic Infections -- which takes place in Boston this year and ends February 14.

### **AIDS Treatment News Backdated for This Issue..... 5**

Our traditional year-end issue was late this year; we backdated it to December, but are reporting the news as of late January, when we went to the printer.

### **Buyers' Club List, December 2002..... 6**

Our annual list of AIDS-related buyers' clubs and contact information.

# AIDS Treatment News

## Subscription and Editorial Office:

AIDS Treatment News  
Philadelphia FIGHT  
1233 Locust St., 5th floor  
Philadelphia, PA 19107  
800-TREAT-1-2 toll-free U.S. and Canada  
fax: 215-985-4952  
email: [aidsnews@aidsnews.org](mailto:aidsnews@aidsnews.org)

**Editor and Publisher:** John S. James

**Reader Services:** Allison Dinsmore

## Statement of Purpose:

*AIDS Treatment News* reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

## Subscription Information: Call 800-TREAT-1-2

Businesses, Institutions, Professional offices: \$325/year. Includes early delivery of an extra copy by email.

Nonprofit community organizations: \$150/year. Includes early delivery of an extra copy by email.

Individuals: \$140/year, or \$80 for six months.

Special discount for persons with financial difficulties: \$54/year, or \$30 for six months. If you cannot afford a subscription, please write or call.

Outside the U.S., Canada, or Mexico, add airmail postage of \$20/year, or \$10 for six months.

Back issues, and discounts for multiple subscriptions, are available; contact our office for details.

Please send U.S. funds: personal check or bank draft, international postal money order, or travelers checks. VISA, Mastercard, and purchase orders also accepted.

## Index 2002, AIDS Treatment News.....

Our annual index for 2002.

## ADAP and Medicaid Financial Emergencies Growing

by John S. James

January 21, 2003: Advocates are working urgently in Congress and state legislatures to prevent decisions that could ultimately deny access to medical care to millions of low or middle income Americans with HIV or other illnesses. As this issue goes to press:

\* 140 AIDS organizations have sent a consensus letter to each U.S. Senator, asking for \$162 million in additional funding for ADAP and other Ryan White programs. The letter notes that many states already have waiting lists for people needing medication under this program -- and Texas may drop many patients already on antiretrovirals. The letter notes that the reason for the crisis is that more people are living longer due to HIV treatment, and also that new drugs are becoming available.

\* On January 17, four U.S. Senators, including, one Republican, co-sponsored a dear-colleague letter on ADAP and Ryan White funding -- addressed to the Chairman and Ranking Member of the Senate Subcommittee on Labor, Health and Human Services, Education. It will be open for additional signatures by Senators for at least several more days.

\* These letters list states that now have waiting lists for people who need treatment for HIV or AIDS -- and note that Texas is considering cutting off as

many as 2,500 people currently receiving treatment through ADAP by June 1 (by retroactively changing eligibility rules so that some of the people already in the program will no longer qualify for ADAP in Texas).

\* In Oregon, 12,000 people will lose Medicaid coverage, including almost 400 with HIV or AIDS. Advocates there are developing a weekly update to provide facts and reduce rumors and speculation.

\* We are starting to hear of herbal and other "alternative" treatments being considered for those who can no longer afford standard medical care.

\* States across the U.S. are facing their worst budget crisis in over half a century -- while the Federal government has also gone from large surpluses to large deficits, even before another war against Iraq.

What Zackie Achmat recently said about South Africa will increasingly apply to the United States: "The country is realizing that people can actually buy life, and that this is unacceptable" (quoted in *The New York Times*, January 13, 2002).

### **What You Can Do**

Millions of Americans already agree about the importance of the AIDS epidemic, and of access to healthcare, but probably 99% of them have *never* been heard by their political representatives, or in any public way. While specialists and organizations are already doing excellent work, we urgently need new advocacy campaigns designed to allow anyone to help, whenever and however they can. These campaigns need more accessible Web sites and action alerts. But even

more importantly, they need political discussion and negotiation among AIDS and other organizations, to develop common actions signed onto by many of the most trusted organizations and individuals working in health.

Fortunately AIDS advocacy already has a long tradition of consensus letters, often signed by dozens of major organizations. But then the letter is delivered to some official, and perhaps a press release goes out, but that's it. Usually these campaigns have had no role for individuals or groups who want to help but cannot be heavily involved. We need similar consensus development for campaigns that the public can run with.

Such campaigns will enable hundreds of thousands of citizens to communicate at least occasionally with their federal, state, and local representatives. Congress and other officials will know that these people care about AIDS and health, greatly improving government commitment and political will. Millions of people already agree on the issues. They need better opportunities to act.

Meanwhile, here are some places to start:

\* Check in with AIDS organizations in your area to see what they are doing, or how they suggest you get involved. This year many statewide advocacy programs will come together in response to the funding emergencies. Statewide campaigns can work with others on Federal issues as well.

\* Get to know your political representatives' main interests, and the staff person(s) handling health. Sometimes it is better to work with the

local office staff, as they are usually more accessible and less rushed than those in Washington. Let them know that you are interested in health, and AIDS. Maybe they can help you understand what is happening in Congress in these areas. You do not need to wait for an action alert, since you may want to start building a working relationship before you need to ask for a vote.

To find the names and contact information of your representative and your state's two senators, see <http://www.congressmerge.com/>. This site also has background information -- including short, practical guidelines for communicating effectively with Congress. And you may want to be informed about your representatives' committee memberships and other major interests, even outside of the health area.

\* To receive national alerts on AIDS treatment access issues (about one per month), join the Treatment Action Network of Project Inform, <http://www.projectinform.org/>.

\* For much more detail on current campaigns, join ATAC, the AIDS Treatment Activists Coalition, <http://www.atac-usa.org/> -- especially the Save ADAP email list (currently about 10 emails per day).

We will closely follow advocacy and activism in 2003, and let you know as consensus-based, user-friendly campaigns are developed.

## **Smallpox Vaccination Followup: IOM Suggests Changes, Widespread Civilian Vaccinations to**

## **Begin**

by John S. James

January 21, 2003: The first phase of voluntary civilian smallpox vaccinations -- for about 500,000 persons who will serve in first-response teams in case of a smallpox attack -- is expected to start in a few days; later, "phase II" will recommend voluntary vaccination for up to 10,000,000 healthcare workers and others. On January 17 the prestigious Institute of Medicine released a number of recommendations for changes in the program. The IOM report, which had been requested by the U.S. Centers for Disease Control and Prevention (CDC), is available at <http://nationalacademies.org/>, along with a press release summarizing important concerns and recommendations.

People with HIV must not be vaccinated against smallpox (unless there is a smallpox attack, in which case the risks and benefits would have to be reconsidered -- or unless a safer vaccine is developed, which will take years). Many others should not be vaccinated as well. In fact, about 30% of the U.S. population is believed to have one or more contraindications, and should not be vaccinated. And since this vaccine contains a live virus, persons with HIV or other contraindications need to avoid close contact (especially household contact) with those who have been vaccinated recently, probably for two to three weeks.

Here are some of the concerns reflected in the IOM report that our readers should know about:

\* Compensation: Who will cover medical and other expenses in case of adverse reactions to the vaccine, or to catching the vaccinia virus from someone recently vaccinated? The Homeland Security Act of 2002 provides a Federal system of compensation for vaccine injuries, but only in cases of negligence in its manufacture or administration (thus shielding the manufacturer from liability). But in cases of adverse reactions where there is no negligence, currently each state is being left to decide about compensation, if any. The IOM report recommends that the CDC try to "clarify each state's workers compensation program's position on coverage for smallpox vaccine-related injuries and illnesses for workers covered under their programs" -- and in other ways to quickly resolve the compensation problem.

[In our view, the compensation issue shows a serious corruption in modern U.S. society -- that

governments and corporations use their power to wash their hands of a public expense and leave it to those least able to pay, in this case the individuals who become ill from adverse reactions. The cost of adverse reactions in this Federal program is clearly a Federal responsibility. We do not need 50 different state systems of rules and litigations, designed under the pressure of the worst state budget crisis in 50 years. Private insurance also may find ways to evade responsibility, under "acts of war" or other clauses. Congress and the president can fix this problem, perhaps by amending the Homeland Security Act to deal with non-negligent vaccine injuries as well as negligent ones.]

\* The IOM report recommends that the CDC use an existing system to actively look for adverse events, instead of waiting passively for such reports to come in. It supports the use of a data safety monitoring board, which is currently planned, but wants it to be more independent of government agencies.

\* Consent forms must clearly explain the risks of vaccination, and the status of compensation in case of adverse events. (Current government planning is to leave consent forms as well as compensation up to the states.)

\* There should be a pause between phase I (500,000 vaccinated) and phase II (10,000,000 vaccinated), to allow for evaluation and corrections if necessary.

\* The CDC should prepare educational material for household

contacts of persons to be vaccinated -- realizing that some of them will be unwilling to disclose contraindications such as HIV or pregnancy, and will need information on how to protect themselves. And those being vaccinated should have confidential opt-out provisions, like blood donors do, so that people will not be socially pressured to receive the vaccine, despite contraindications they are unwilling to disclose. (Blood donors who suspect they might have HIV or other undisclosed illness, but have been pressured to donate and are unwilling to opt out in front of others, can quietly check a box on a form and continue through with the donation process, knowing that their blood will never be transfused into anybody.)

**Note: Healthcare Workers  
Vaccination,  
HIV Testing and Disclosure**

On January 15 Lambda Legal, AmFAR, and the Gay and Lesbian Medical Association issued a joint statement on HIV testing and disclosure during the vaccination program. It is available at: [http://www.thebody.com/lambda/smallpox\\_vaccine.html](http://www.thebody.com/lambda/smallpox_vaccine.html)

**Boston: Community  
Forum on Retroviruses  
Conference, Feb. 14**

Search for a Cure will sponsor a free community forum on treatment news from the important 10th Conference on Retroviruses and Opportunistic Infections, on the last day of the conference, February 14, 1-3 p.m. at the Sheraton Boston hotel.

Lunch will be provided. Advance registration is required; to register, call Search for a Cure, 617-536-2474 (OK to leave a message if necessary), or register by email, [hope@sfac.org](mailto:hope@sfac.org). In either case include your name and a way to contact you, and note that you are registering for the community meeting on February 14th.

The summary on new treatment information will be presented by Cal Cohen, M.D., with a panel including Sigal Yawetz, M.D., and treatment information specialists Jules Levin of NATAP, George Carter of FIAR, and John S. James of *AIDS Treatment News*. This meeting is funded by Search for a Cure; the Retroviruses conference donated the room.

For more information on Search for a Cure, see <http://www.searchforacure.org/>.

***AIDS Treatment News  
Backdated for This  
Issue***

Our 2002 year-end issue was delayed, so this issue was backdated December 27, 2002 (the last Friday of the year), although it actually went to the printer on January 23, 2003. We used the December date so the year-end 2002 index will be filed correctly with the other 2002-dated copies in libraries, consistent with previous years. However, the news reported in this issue is current as of late January.

The backdating will not affect the total number of issues received by

subscribers.

## **Buyers' Club List, December 2002**

*AIDS Treatment News* publishes a buyers' club list each December. For a short overview and introduction to the meaning, history, and services of these organizations, see *AIDS Treatment News* #309, December 18, 1998.

We focus on buyers' clubs specializing in HIV (we also included Rainbow Grocery in San Francisco, because of its extensive selection of supplements and excellent information about them). All the organizations listed below are nonprofit. Most can provide products by mail order. Most have fact sheets or other information, and some have a nutritionist or other expert available at certain times to answer questions. Some offer financial assistance with purchases if necessary. Most are open to the public, but some require membership (which may involve an annual fee, or be restricted geographically or in other ways). Call ahead for current information.

### **Arizona**

Being Alive Buyers' Club

<http://www.apaz.org/> (click "Buyer's Club")  
chadO@apaz.org or robertS@apaz.org  
1427 North Third St., Phoenix AZ 85004  
602-253-2437x136 or x138, fax: 602-253-5577

Travis Wright Memorial Buyers' Club  
Southern Arizona AIDS Foundation  
<http://www.saaf.org/>  
wellness@saaf.org  
375 S. Euclid Ave, Tucson AZ 85719  
800-771-9054 or 520-628-7223  
fax: 520-628-7222; TTY: 800-367-8937

### **California**

Rainbow Grocery Cooperative (20% PWA discount, with the Helping Hand card)  
<http://www.rainbowgrocery.coop/> (or  
<http://www.rainbowgrocery.org/>  
vitamins@rainbowgrocery.org  
1745 Folsom St., San Francisco CA 94103  
415-863-0620

### **Colorado**

Denver Buyers' Club  
pwacolo@aol.com

*AIDS Treatment News* #387, December 27, 2002  
800-TREAT-1-2

1290 Williams St., Suite 102  
Mailing address: P.O. Box 300339, Denver CO  
80203-0339  
303-329-9379, fax: 303-329-9381  
Bilingual Spanish/English TTY: through operator

### **District of Columbia**

Carl Vogel Center  
[cvchiv@carlvogelcenter.org](mailto:cvchiv@carlvogelcenter.org)  
1012 14th St. NW, Suite 700, Washington DC  
20005  
202-638-0750, fax: 202-638-0749

Membership: annual cost \$25 (includes a BIA test, reduced prices for massage and acupuncture, an educational symposium, a newsletter, and reduced prices for supplements).

The Carl Vogel Center now offers mental health services and treatment education.

### **Georgia**

AIDS Treatment Initiatives  
<http://www.aidstreatment.org/>  
[info@aidstreatment.org](mailto:info@aidstreatment.org)  
159 Ralph McGill Blvd. NE Suite 510, Atlanta  
GA 30308-3311  
888-874-4845 or 404-659-2437  
fax: 404-450-9412

### **Massachusetts**

Treatment Information Network's/Boston  
Buyers' Club  
<http://www.bostonbuyersclub.com/>  
[info@bostonbuyersclub.com](mailto:info@bostonbuyersclub.com)  
Boston Living Center, 29 Stanhope St., 3rd  
Floor  
Boston MA 02116  
800-435-5586, or 617-266-2223  
fax: 617-450-9412

### **New York**

DAAIR (Direct Access Alternative Information Resources)  
<http://www.daair.org/>  
email: [info@daair.org](mailto:info@daair.org)  
119 W 23rd St., Suite 404, New York, NY  
10011  
212-255-9280  
fax: 212-255-9280

Note: The largest buyers' club in the United States. Membership by sliding scale, \$5, \$10, or \$25 per year; new members receive treatment information pack. Also, "Preventing and Managing Side Effects and HIV Symptoms"

is available at <http://www.daair.org> (no membership required -- click the Countering Toxicities button on the home page), or by mail by request if necessary.

## **Texas**

Houston Buyers' Club  
<http://www.houstonbuyersclub.com/>  
 info@houstonbuyersclub.com  
 3400 Montrose Blvd. #604, Houston TX 77006  
 800-350-2392  
 713-520-5288, fax: 713-521-7419

Note: *How to Manage Side Effects*, a 48-page booklet by Lark Lands, Michael Mooney, Nelson Vergel, and others is available without charge. You can request a copy by phone, mail, or email.

## **Index 2002, AIDS Treatment News**

Aaron Diamond Research Center	384
Abbreviated Guide ... HIV	380
Access to care	387
Achmat, Zackie	387
ACT UP	385
ACTG 384 trial changes	382
Activism	377
Activism	379
Activism	385
Activism	387
ADAP crisis	381
ADAP crisis	382
ADAP crisis	386
ADAP crisis	387
ADAP waiting list advice	381
ADAP	380
Advocacy	387
African Services Committee	385
AIDS Drug Assistance Program (see ADAP)	
AIDSWatch lobbying	380
Amprenavir approved	378

Anti-HIV factor	384
Atazanavir	379
Avascular necrosis	379
Barcelona conference take-home messages	382
Barcelona conference visa problems	381
Barcelona conference Web sites	381
Barcelona online reports	382
Benefits issues	377
Bone problems	379
Buyers' club list	387
Chinese activist, Dr. Wan Yanhai	383
Coca Cola protest	384
Conferences and meetings list	378
Congress	387
Cost of international conferences	381
Counterfeit drugs	380
C-Reactive Protein	385
d4T -- side effects	378
d4T and lipoatrophy	378
Deca Durabolin availability problems	381
Defensins	384
Doctors Without Borders	385
Doha, Qatar	386
Drug interactions	377
Drug pricing	377
Efavirenz once daily	378
Epogen	380
Facial injections	378
Fundraising	377
FUZEON (see T-20)	
Global Fund	379
Government AIDS Web site	386
Grossman, Dr. Howard, interview	383
Guidelines on metabolic complications	
	385